Self-perceived health status and mental health outcomes in young adults born with less than 1000 g

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Abstract: AIM: To assess self-perceived health status and mental health outcomes of former extremely low-birth-weight (ELBW) infants at young adulthood compared with community norms and to analyse predictors of poor outcome. METHODS: Fifty-five ELBW adults, 18 men (33%), with median (range) gestational age of 28.7 (25.0-34.0) weeks and birth weight of 930 (680-990) grams, born in Switzerland, were included. They self-rated their health status and mental health at a mean (range) age of 23.3 (21.8-25.9) years. Health status was measured by the Medical Outcomes Study Short Form-36 questionnaire and mental health by the Brief Symptom Inventory. RESULTS: The mean scores for both outcome measures were in the normal range. However, the study group self-rated significantly higher physical health status and lower mental health status compared with the community norms, and scores for self-perceived mental health tended to be worse in the former. ELBW adults reported more problems in socio-emotional role functioning compared with the community norms. Female sex was associated with poorer and bronchopulmonary dysplasia with better mental health status. CONCLUSION: Health status and mental health of former ELBW adults were overall satisfying. However, the comparison with the community norms revealed differences, which may be important for parental and patient counselling and developing support strategies.

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Self-perceived health status and mental health outcomes in young adults born with less than 1000 g

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Short title: Mental health in former ELBW infants

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Abstract

Aim: To assess self-perceived health status and mental health outcomes of former extremely low birth weight (ELBW) infants at young adulthood compared to community norms and to analyze predictors of poor outcome.

Methods: 55 ELBW adults, 18 males (33%), with median (range) gestational age 28.7 (25.0-34.0) weeks, birth weight 930 (680-990) grams born in Switzerland were included. They self-rated their health status and mental health at a mean (range) age of 23.3 (21.8-25.9) years. Health status was measured by the Medical outcomes study short form-36 questionnaire, mental health by the Brief Symptom Inventory.

Results: The mean scores for both outcome measures were in the normal range. However, the study group self-rated significantly higher physical health status and lower mental health status compared to the community norms, and scores for self-perceived mental health tended to be worse in the former. ELBW adults reported more problems in socio-emotional role functioning compared to the community norms. Female sex was associated with poorer and bronchopulmonary dysplasia with better mental health status.

Conclusion: Health status and mental health of former ELBW adults were overall satisfying. However, the comparison with the community norms revealed differences which may be important for parental and patient counselling and developing support strategies.

Keynotes

Survivors of extreme prematurity show higher rates of poorer cognitive attainment and behavioural problems at adolescent age. However, little is known about their self-perceived health status and overall psychological adjustment in adulthood. Our study showed overall satisfying results in both outcome measures in early adulthood; however, former extremely low birth weight adults self-rated their mental health status lower than the community norms, with the socio-emotional domains being specially affected.

Keywords

Extremely low birth weight, health status, Medical outcomes study short form-36, mental health, Brief symptom inventory

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Conflict of interest

All authors declare no actual or potential conflict of interest in relation to this manuscript.

Introduction

Traditionally follow-up of very low birth weight infants was focused on growth and neurodevelopment. Only recently quality of life (QoL) and mental health evaluated by the individuals themselves were introduced as outcome measures (1). Survival rates in extremely low birth weight (ELBW) and extremely preterm infants significantly increased in the last three decades (2). There is concern whether this change will affect QoL and psychological functioning in survivors. Previous studies report lower health utility scores in formerly ELBW school-aged children and adolescents compared with peer controls (3). It seems however, that the effect of prematurity on QoL diminishes over time (1) and that in young adulthood self-rated QoL is comparable to normal birth weight peers (4). However, there is no agreement on this topic in the literature. In fact, differences in self-perceived QoL in preterms are still observed at young adult age in some studies, demonstrating both lower (5, 6) and higher (7) scores in diverse dimensions compared to controls. While at adolescent age an increased risk of poorer cognitive attainment, attention deficit, and hyperactivity disorder in very low birth weight survivors persists (8), little is known about the overall psychological adjustment in adulthood and specifically in former ELBW subjects. The objective of our study was to evaluate the self-perceived health status, as a measure of QoL, and mental health, as well as predictors for poor outcome in adults born with a birth weight below 1000 g in Switzerland between 1983 and 1985. As poorer neurodevelopmental outcome in preterms is known to be associated with lower gestational age and birth weight, we hypothesized that both outcome measures should be lower in formerly ELBW compared to community norms. Moreover, we hypothesized that the risk factors known to be associated with unfavourable neurodevelopmental outcome in preterms should be associated with lower health status and mental health scores in our study group.

Patients and methods

Study Cohort

The original study group included all live-born infants weighting less than 1000 g at birth born between January 1, 1983 and December 31, 1985 in Switzerland. In this three year period 223'053 infants were born alive, thereof 390 (0.17%) with a birth weight below 1000 g. Among them, 119 infants were discharged from hospital alive and followed up prospectively from the respective Swiss follow-up centre until 10 years of age. We tried to trace these 119 subjects and could find 65. Fifty-four had moved from their last address, left Switzerland or changed family name after marriage. Five subjects refused to participate in the study and 5 did not send back the questionnaire even after two reminding letters and a phone call. Finally, 55 (47% of the original cohort, 85% of those who could be traced) took part in this survey, 18 males and 37 females.

Procedure

All subjects who could be traced were contacted by mail. Those who were willing to participate received a questionnaire that included two validated measures of health status and mental health. Relevant neonatal and demographic information collected in a Swiss national database were selected (Swiss Society of Neonatology, www.neonet.ch). This information included sex; gestational age; birth weight; small for gestational age status, defined as a birth weight below the 10th percentile for gestation); arterial cord pH; 5' Apgar score; duration of mechanical ventilation; intracranial haemorrhage defined according to Papile and associates (9); retinopathy of prematurity defined according to criteria proposed by the International Committee for the Classification of Retinopathy of Prematurity ; bronchopulmonary dysplasia, defined as additional need for supplemental oxygen at 36 weeks postmenstrual age; and nationality of the parents. Information about regular medication use, chronic illness, need for functional or psychological therapy as well as data on social life was collected with a standard questionnaire.

Measures

Health status

To assess self-reported health status, the Medical outcomes study short form - 36 item questionnaire was used (10). This questionnaire is a generic measure of health status in adults that assesses the following

eight distinct domains: physical function, role limitations due to physical problems, bodily pain, general health perception, mental health, role limitations due to emotional problems, vitality, and social functioning. Each subscale is standardized into a score from 0 to 100, with higher scores indicating better health status. The subscales can be summarized into a physical and a mental component summary score, which are standardized with a mean of 50 (SD = 10). The Medical outcomes study short form-36 has consistently been reported to have excellent psychometric properties (10). In this study, the German and French versions were used with age- and sex-adjusted reference data provided from the respective community samples (11, 12). The time frame was set to the past 4 weeks before assessment. In the current sample, internal consistencies of all subscales and summary scores were excellent to good, with Cronbach's α between .71 and .92.

Mental health

To assess self-reported mental health, the Brief symptom inventory was used (13). This measure yields a global index, i.e. Global severity index, in both patient and non-patient populations. The main indices are derived from fifty-three 5-point scale items which are linked to nine primary symptom dimensions; i.e. somatisation, obsessive-compulsive behavior, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. The Brief symptom inventory measures current psychological status and distress experienced in the past seven days, including the day the Brief symptom inventory was completed. The higher the main indices value the heavier the distress. For its German versions age- and sex-adjusted reference data of the Brief symptom inventory were provided from a community sample of 600 Germans (14). In the absence of a published French version the Brief symptom inventory questionnaire was cross-cultural adapted and translated into French for the Swiss population and back translated to German by someone unaware of the original version. The two versions were compared to ensure meaning was retained. The reliability analysis revealed satisfying degree of internal consistency for the Global severity index with a Cronbach's α=.95, and α ranging from .62 to .78 for the nine symptom dimensions of the Brief symptom inventory.

Statistics

Statistical analyses were performed with SPSS 18.0 (SPSS Inc., Chicago, USA) as follow: X^2 test and Mann-Whitney U-test were used to compare frequencies and not normally distributed variables in study subjects and dropouts; one-sample t-test to compare health status and mental health scales with the community norms, and effect sizes were evaluated based on established conventions (15). Normal distribution was tested with Kolmogoroff-Smirnov-Goodness-of-Fit-Test. In order to evaluate the relevance of neonatal and socio-demographic subject's variables in predicting health status as well as mental health, multivariate linear hierarchic regression analyses were used.

Ethics

The study protocol was approved by the institutional ethical review boards and by the Swiss Federal Commission for Privacy Protection in Medical Research. Written informed consent was obtained from the participants.

Results

Characteristics of study cohort

The data of the study subjects compared with those of the non-participants are given in Table 1. Both groups did not differ significantly with respect to the enlisted perinatal and socio-demographic variables. Study subjects completed the questionnaires at a mean age of 23.3 (range, 21.8 – 25.9) years. Twelve subjects (22%) suffered from a chronic illness at the study period, one of them suffered from cerebral palsy, and 11 (20%) needed regular medication. At assessment, 32 (58%) subjects reported at least one incidence of functional and 17 (31%) of psychological therapy during life-time. Regarding education, 2 (3%) study subjects were attending college; 17 (31%) had a bachelor's degree; 13 (24%) had a higher education degree; 16 (29%) subjects had a secondary education degree; 4 (7%) had completed the local obligatory schooling; and 3 (6%) had attended a special school for mentally or physically disabled children.

Self-reported health status

Table 2 reports means and SDs of the Medical outcomes study short form-36 in ELBW adults as well as the results of the comparison with the community norms. Formerly ELBW adults rated significantly

higher for physical component summary and lower for mental component summary compared to the community norms. Among the eight domains scores were significantly higher for 'bodily pain', 'general health', and lower for 'social functioning. A medium effect size was observed in all significant results.

Self-reported mental health

Table 3 lists means, SDs of the Brief symptom inventory as well as the results of the comparison with the community norms. The comparison of the scores for the Global severity index in the study group to the community norms revealed no significant difference. Among all symptom dimensions of the Brief symptom inventory, the study group self-scored significantly higher compared with the community norms in 'somatisation', 'interpersonal sensitivity', 'hostility' and 'psychoticism'. A medium effect size was observed just in the last two of them. Self-rated mental health correlated well with the mental health status scores of the Medical outcomes study short form-36 ($r=-0.57$, $p<0.001$).

Predictors of outcome

As we were looking for predictors for unfavourable outcome and as the study group scored significantly lower in the mental component summary of the Medical outcomes study short form-36 compared to norms, we analyzed predictors only for this variable. Table 4 summarizes statistics for the corresponding regression model. Female sex was a significant risk factor for lower mental health status. Concerning the neonatal factors, we observed that bronchopulmonary dysplasia was a predictor for better self-reported mental health status. No other factor was associated with this outcome measure.

Discussion

Outcome

In this study young adults born in the early 1980s with a birth weight below 1000 g reported a lower mental and a better physical health status compared to community norms. In line with this, self-rated mental health was impaired in some dimensions. These findings are not in full agreement with our initial hypothesis and with previous studies on outcome of extreme preterms in adult age and born during the same or a fairly close period as our study subjects. Saigal and associates reported a successful transition to adulthood in the majority of longitudinally followed former ELBW infants (16) and revealed no

relevant difference in self-reported quality of life (QoL) in these subjects compared to normal birth weight subjects at age 23 years (4). In our cohort however, subjects experienced good physical but poor mental health status, suggesting different adjustment to these two aspects of life. The difference to the result of Saigal may be due to a different instrument for the assessment of QoL. Among three studies assessing self-reported health status with the Medical outcomes study short form-36 in formerly preterm adults as a measure of the subject's QoL, one reported better outcome for the domains 'bodily pain' and 'general health' (7), the other showed a worse perception of 'physical functioning' (6, 17), and of 'general health' (17), respectively, compared to term controls. While results of the first study are in agreement with ours, all papers did not differentiate between physical and mental components of health status.

Subjects of our study presented with higher problems in the socio-emotional role functioning, which is revealed by the lower scoring in the related Medical outcomes study short form-36 ('social functioning') and Brief symptom inventory ('interpersonal sensitivity', 'hostility') domains. Surprisingly, the analysis of the correlation between the domains 'social functioning' of the Medical outcomes study short form-36, the dimensions 'interpersonal sensitivity' and 'hostility' of the Brief symptom inventory and the socio-demographic characteristics of the subjects, as living in partnership or being part of a friendship group, revealed no significant result (data not shown).

The risk for behavioural and psychological problems in childhood and adolescence increases with decreasing gestational age and weight at birth, formerly preterm teenagers displaying more internalizing and externalizing problems, as well as attention deficit and hyperactivity, than term controls (18). Direct comparisons between our findings on mental health and those of other studies are difficult, because of the sparseness of data concerning the outcome of preterms at adult age (19). However, results from two recent large studies from Sweden and Denemark suggested that preterm birth constitutes a single independent risk factor for a range of psychiatric diagnoses at young adult age (20, 21).

Although we have observed no difference between the averaged Global severity index of our study subjects and that of the community norm, a higher self-reported distress in 4 among 9 psychological symptom dimensions was observed. This is in line with the increase in internalizing and externalizing

behavioural and psychological problems among very low birth weight survivors in young adulthood compared to controls, which has already been observed by others based on self- and parent-reports (22).

The higher scores in the self-reported physical health status observed in our study subjects are surprising considering that our study group had a higher prevalence of chronic illness and regular medication need (22%) than the overall Swiss population (16%) (Swiss Federal Statistical Office, unpublished data). Thus, it is important to differentiate the physical health of our ELBW, which is apparently more affected than in the general population, from their self-perception of the physical health dimension, which is higher than in the community norms. This phenomenon, which is known as response shift, has been previously reported as psychological adaptation in chronically ill patients (23). It appears that subjects change their internal standard of conceptualisation of QoL over the course of time (24) as a buffer to the stressful impact of their physical condition. This might be a relevant aspect to take into account, while assessing QoL in formerly preterm adults.

Outcome predictors

The identification of female sex as a risk factor for lower mental health status is in agreement with epidemiological studies on the overall population in western countries, showing this demographic variable as a risk factor for psychological morbidities and lower QoL in adulthood (25). In the preterm population the male sex has been described at higher risk for developmental impairment from early childhood to adolescence (26-28). Our findings suggest that after having undergone puberty, self-perceived physical health status of former preterm adults without major neurological impairment approaches and overcomes that of the community.

The neonatal outcome factor ‘bronchopulmonary dysplasia’ was associated with a better self-perceived mental health status, which is surprising at first view. Similarly, young adult patients with other chronic respiratory problems as asthma, report an improvement in their QoL along age (29). We interpret this result in line with the previously mentioned response shift among patients with chronic illness, while the role of this neonatal complication as a possible protective factor for favourable outcome appears definitively less plausible.

In our study, non-Swiss nationals tended to be more at risk for lower self-perceived mental health status. This finding is in agreement with previous literature on adult patients with chronic diseases, which shows ethnicity differences in the perception of QoL and health status, minority groups scoring lower QoL than majorities (30). However the socioeconomic status of the families of the study subjects was not associated with the outcome measures. This is not in agreement with previous literature on outcome predictors in preterm infants (31), but might be due to the small size of the studied group and the wide socioeconomic status range. Similarly, the lack of any association between the subjects' gestational age and the outcome measures could be explained by the wide range of this neonatal factor in the study group. It has been already observed, however, that the effect of prematurity on QoL seems to decline over time (1).

The strengths of this study are the consistency of the collected data; and the use of two validated questionnaires enabling comparisons with community norms and other countries. However, the absence of contemporary Swiss controls and the consequent use of historical German and French norms published between 1997 and 2001 concerning our outcome measures can be questioned as study limitation. While a cross-cultural bias seems unlikely, because Germany, France and Switzerland are European countries with similar social (as well as cultural and economic) structures, a historical context bias is possible. Another limitation of our study is the high dropout rate and the consequent small size of the studied group. Even if there was no difference between our study subjects and dropouts with regard to perinatal and socio-demographic variables, a bias in favour of the ELBW participants cannot be completely excluded.

In conclusion, the comparison with the community norms revealed that formerly ELBW at young adulthood have lower mental and better physical health status, as well as lower self-rated mental health, based on self-reports. During early adulthood some domains are adjusted but not all, the socio-emotional domain was specially affected. These findings, together with the identification of two outcome predictors, are important for parental and patient counselling and may be helpful in order to develop support strategies for this population group.

List of abbreviations

HRQoL Health-related quality of life

ELBW Extremely low birth weight

SD Standard deviation

Table 1: Comparison between study subjects and dropouts.

	Study subjects (n=55)		Dropouts (n=64)		χ^2	U	*p*
Female, n (%)	37	(67)	37	(58)	1.13		.29
Gestational age, median (range), weeks	28.7	(25.0 – 34.0)	28.0	(23.4 – 34.0)		1510.5	.18
Birth weight, median (range), grams	930	(680 – 990)	890	(640 – 990)		1459.5	.11
Small for gestational age, n (%)	26	(47)	24	(37)	1.36		.24
Arterial cord pH, median (range)	7.24	(6.96 – 7.44)	7.28	(7.02 – 7.40)		522.5	.16
5' Apgar, median (range)	7.0	(3 – 10)	7.0	(0 – 10)		1348.0	.27
Days on respirator, median (range)	4.0	(0 – 158)	1.0	(0 – 59)		1634.0	.58
Intracranial haemorrhage > 2°, n (%)	2	(4)	6	(9)	1.55		.21
Retinopathy of prematurity > 2°, n (%)	1	(2)	3	(5)	0.72		.40
Bronchopulmonary dysplasia, n (%)	10	(18)	17	(26)	1.07		.30
Cerebral palsy, n (%)	1	(2)	1	(2)	.88		.35
Swiss nationality, n (%)	41	(74)	41	(64)	1.94		.16
Family SES, median (range)	7.0	(0 – 12)	7.0	(0 – 12)		1458.5	.90

Table 2: Physical and mental component summary and subscales of the Medical outcomes study short form-36: comparison between study group and age- and gender matched community norms.

	α	Study subjects (n = 55)			Community norms		t	p	d
		Mean (SD)		Range	Mean (SD)				
Physical component summary	.89	54.95	(7.18)	30.88 64.99	52.19	(6.46)	2.83	<.01	.40
Mental component summary	.87	46.21	(10.96)	29.10 62.21	50.29	(8.00)	-2.73	<.01	-.43
Physical functioning	.88	94.28	(12.75)	19.00 100.00	94.46	(11.39)	-.10	.92	-.22
Role-physical	.71	89.09	(22.96)	0.00 100.00	90.42	(23.60)	-.43	.67	-.06
Bodily pain	.92	83.35	(23.27)	12.00 100.00	73.63	(23.68)	2.78	<.01	.41
General health	.77	78.42	(19.48)	30.00 100.00	73.11	(.83)	2.02	<.05	.30
Vitality	.78	57.36	(19.05)	20.00 100.00	60.54	(.42)	-1.24	.22	-.18
Social functioning	.79	80.23	(24.02)	25.00 100.00	88.72	(17.49)	-2.62	.01	-.40
Role-emotional	.77	84.57	(30.17)	0.00 100.00	92.34	(21.05)	-1.89	.06	-.30
Mental health	.86	68.73	(18.73)	19.00 100.00	73.31	(15.23)	-1.81	.08	-.27

α = Cronbach's alpha; d = Effect sizes according to Cohen (15): 0.2, small effect size; 0.5, medium effect size; >0.8, large effect size.

Table 3: Comparison of mental health scores between study cohort and age- and gender matched Community norms (Mean = 50, SD = 10) as measured by the Brief symptom inventory.

		Study subjects (n = 55)						
	α	Mean	SD	Range		t	p	d
Global Severity Index	.95	53.77	15.03	26.0	80.0	1.86	.07	.30
Somatisation	.69	53.13	11.46	39.0	80.0	2.02	<.05	.29
Obsessive-compulsive	.75	52.33	12.82	35.0	76.0	1.34	.19	.20
Interpersonal sensitivity	.66	53.18	11.62	38.0	80.0	2.03	<.05	.21
Depression	.88	53.17	13.25	40.0	80.0	1.76	.09	.27
Anxiety	.72	52.70	12.32	37.0	76.0	1.61	.11	.24
Hostility	.73	55.11	11.91	37.0	80.0	3.18	<.01	.47
Phobic anxiety	.66	51.24	10.60	44.0	80.0	.87	.39	.12
Paranoid ideation	.79	52.84	10.76	40.0	80.0	1.96	.06	.27
Psychoticism	.62	54.82	11.87	43.0	80.0	3.01	<.03	.44

α = Cronbach's alpha; d = Effect sizes according to Cohen (15): 0.2, small effect size; 0.5, medium effect size; >0.8, large effect size.

Table 4: Summary of multiple regression analyses for predictors of mental component summary score of the Medical outcomes study short form-36 in formerly extremely low birth weight adults.

	B	SE	β	T	p
Female gender	-6.17	3.01	-0.27	-2.05	.04
Birth weight	0.00	0.02	0.02	0.14	.89
Bronchopulmonary dysplasia	10.97	3.88	0.37	2.82	.01
Swiss nationality	6.20	3.47	0.24	1.79	.08
Chronic disease	-4.00	3.50	-0.15	-1.14	.26

Note: F=3.56; p = .009; R^2 = .29; R^2 adjusted = .21.

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